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Decision-making in paediatric care – an overview with reference to nursing care

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Abstract

The purpose of this overview of previous articles on decision-making in paediatric care was to identify important aspects of possible use in clinical practice and to obtain a base for future research. A literature review was undertaken utilising snowball sampling to identify papers due to the diversity within the area of decision-making in paediatric care. The databases PubMed and CINHAL were used. The search was limited to articles published in English during the period 1994 – 2004. The analysis entailed a series of comparisons across articles focusing on major areas of inquiry and patterns of results. Various levels of decision-making are described, as these seem to form a basis for how decisions are made. Concepts found to be of importance for decision-making are described under the following headings: competence, the child's best interests, knowledge, values and attitudes, roles and partnership, power and economy. Further research is suggested.

Key words: child, decision-making, health care, literature review

INTRODUCTION

Children are most often defined as being in the age group 0-19 years. In 2000, there were about 2.2 million people, or 24% of the Swedish population, in that age group.[1] There is a long-running, unresolved debate about children's rights in decision-making that is actualised daily in clinical practice. Since adoption of the UN Convention on the Rights of the Child in 1989,[2] efforts have been made to implement the intentions of the Convention.

Legal issues

Parents are used as proxies for children when the child is not judged to be competent or to have the legal right to make a decision. According to Beauchamp & Childress (p 102), [3] *"A surrogate - or proxy decision maker, must determine the highest net benefit among available options assigning different weights to interests the patient has in each option"*. To be able to make decisions for incompetent patients (including new-borns), the following qualifications are suggested by Beauchamp and Childress(p 154): [3]

"(1) ability to make reasoned judgements (competence), (2) adequate knowledge and information, (3) emotional stability, and (4) a commitment to the incompetent patient's interest that is free of conflicts of interest and free of controlling influence by others who may not act in the patient's best interest".

Competent adults are allowed to define their own concept of best interests even if their views about what would benefit them are very different from those of the rest of the society. Children and young people have not generally been given the same options. The UN Convention on the Rights of the Child[2] was adopted by the UN in 1989 and ratified by 177 nations in 1995. The Convention formulates the needs of children and young people in terms of human rights and sets minimum standards for children so that they are recognised as a group to whom human rights legislation applies. The overall message can be summarised as follows: children are to be respected, and adults, parents and adults working with children have a responsibility to ensure that the structures, systems and programmes that are enacted enable children to claim their rights. Sweden (1979), Finland (1983), Denmark (1985), Norway (1987), and Austria (1989) have all adopted laws that prohibit parents from hitting their children. The European Convention on the Exercise of the Rights of the Child,[4] and the Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine,[5] point out that in all actions concerning children, the best interests of the child should be a primary consideration. In ten articles, the European Association for Children in Hospital (EACH)[6] has formulated children’s rights in hospital and emphasised the child’s right to information and participation in accordance with age and maturity.

The child in a social context

Different but not mutually exclusive frameworks in developmental psychology have described children’s development into young people. The first is by a series of built-in cognitive constraints and organisational principles determining the hypothesis children entertain, the knowledge they acquire and the behaviour they produce, as characterised by an internal set of cognitive restructuring that determines the ways children’s thought processes and understanding develop. The second is a social construction where children's nature, content of knowledge, and behaviour are influenced by their social and cultural context (p 47-48). [7] The status different cultural communities bestow upon children will be reflected in differences in the children's sense of belonging.

Jenkins[8] describes four constructions of childhood covering specific perspectives where children can be seen as possessions, as subjects, as participants, and as citizens. The view of children as possessions and as the property of parents or other adults, with the child having no rights independent of them, still exists, and is especially common regarding girls. The view of children as subjects implies that the child is in need of protection by adults. Children have rights, but the rights are decided upon and enforced by adults. This model of the child is closely associated with the theory of cognitive development, where children are considered to be dependent, irrational and vulnerable for a considerable length of time. Viewing children as participants means that children have the right to be consulted about any decision that concerns them in economic, social, political, or cultural terms. Viewing children as citizens means that the child is an active citizen and thus has the right to hold and to express views, to make choices, and to take action independently of parents and adults.

Children in paediatric care

Historically, professionals were the major decision-makers, and it is still assumed that they know how children think and feel about treatment and care.[3] Children and young people in need of care are particularly vulnerable. Their future depends on the legal system as well as on social welfare and their parents and family.

Communication between the persons involved and the systems is vital for the child.[9] There are many reasons for involving children and adolescents in decisions regarding their care and treatment. Ethical principles of autonomy and self-determination apply to children as well as adults. Children's involvement in decisions will improve open communication among the doctor, nurse, patient, and parent, which may directly facilitate the child's co-operation in care and treatment. Furthermore, if children are involved they get information and may get a sense of control, which may in turn enhance their positive adjustment.[10,11] Finally, involving children in the decision-making process demonstrates respect for children and may provide opportunities for further development and decision-making capabilities.[12]

When decisions are to be made in paediatric care, comprehensive collaborative work is involved and multiple confounding factors are included. The topic has been written about extensively, especially in the fields of law and social systems. However, this is a difficult area comprising several concepts that may be interpreted in various ways in health care. An overview of previous literature on decision-making in paediatric care in which important aspects are identified might be useful for clinical practice and provide a base for future research.

AIM

In this article we will give an overview from a nursing perspective of how decision-making in paediatric care has been described and identify aspects of importance that influence how decisions are made concerning the hospitalised child. We will also try to identify gaps in that knowledge and suggest methods for expanding and enhancing our understanding in this area.

METHODS

A literature review was undertaken utilising snowball sampling to identify papers due to the diversity within the area of decision-making in paediatric nursing care. The PubMed and CINHAL databases were used. The search was limited to articles published in English during the period 1994 – 2004. The results of the searches are shown in tables 1 and 2**.** A review of related articles and reference lists resulted in 24 more articles. Both authors read all articles independently, and 49 of the articles were found to be relevant for our purpose. As the aim of the literature review was exploratory rather than to determine the answer to a specific research question, it was conducted in a systematic manner but not as a true systematic review. Table 3 gives an overview of the articles. The 29 original articles described 28 different studies.

Insert tables 1, 2, and 3 about here

Each article was reviewed based on the following questions: Who is involved in the decision? Which factors influence the decision? In what way are children and parents involved in the decision? The analysis entailed series of comparisons across the articles focusing on major areas of inquiry and patterns of results. Thereafter, the aim of the analysis was to identify and synthesize the results. Concepts found to be important for decision-making were chosen as headings in this article.

RESULTS

When decisions have to be made concerning a hospitalised child, three parties are involved, the child, the parents and various staff members. These parties may constitute different groupings. Doctors and nurses often, but not always, have the same opinion. Parents are often, but not always, united in their decision. Parents and professionals may have opinions that differ from that of the child. In the ideal situation, after receiving information and communicating with one another, all concerned will reach a common decision. Unfortunately, in many situations it is more or less obvious that there is no agreement. The final decision will depend on the influence of the various parties.[13,14,15]

The results will be presented under the following headings describing concepts found to be of importance: competence, the child's best interests, knowledge, values and attitudes, roles and partnership, power and economy. First, however, various levels of decision-making will be described, as these seem to constitute a basis for how decisions are made.

Levels of decision

With increasing age and maturity, children should be able to participate to an increased extent in decisions about their care. However, children may not realise they have the possibility of participating in decision-making unless they are told that this is so, and some children may not wish to participate.[16] We usually talk about three levels of participation in decision-making, the highest being consent.[16] At this level children are supposed to be mature enough to receive and understand information and to give voluntary consent to the treatment or procedure proposed.

Their decision must be based on knowledge about the proposed decision as well as the consequences, and must be voluntary, volitional and rational.[17] Obtaining consent is a process rather than simply agreement about a certain act. To give one's consent, legally one must be 18 years of age or older, but many younger children are competent to give their consent. At the age of 12, children are usually considered to understand the implications of the process of informed consent.[18] Children and adolescents have different developmental capacities compared with adults. They differ in their perceptions of benefits and risks, which makes consent difficult, and they are also less resistant to social influence and affected by the opinions of parents, family members and hospital staff .[19]

The giving of assent by minors is a way of involving them in decision making.[17] Assent is the lowest level of consent. The child agrees with decisions made by others, and does not require much knowledge and understanding. Assent is supposed to be a middle ground between consent and not being involved in the consent process.[20] Assent is an interactive process between the child and adults, and requires that the child has been informed about what is going to happen and has agreed to the procedure. The child will have some control regarding choices, although others make the decisions. It must be clear to the child that he or she will be given information but will not have the power to veto the proposed action. If the decision has already been made, there is no point in seeking the child's assent; the child's view must not be sought if there is no intention to weigh that view seriously.[17]

Dissent involves a difference of opinion and a lack of agreement between the child and the other parties. It requires a certain understanding of the proposed action and its effects. If there is evidence that the child understands and has sufficient knowledge about the issue, the child’s dissent ought to be taken seriously.[16] It might be argued that even small children dissent when, for example, they refuse to get an injection or other painful treatment. This refusal is, however, not based on knowledge and understanding, but more on the fear of undergoing a threatening procedure and the inability to weigh short-term pain against long-term benefits.

An interesting question arises when a child who is judged as competent enough to give informed consent to a procedure refuses to do so. How such a situation will be handled depends on several factors, an important one being the seriousness of the decision that will be made. If it involves something that is life threatening, more emphasis will be placed on determining whether the child has actually understood the consequences of the decision in both the short and the long term. The child’s competence may then have to be further investigated.[21]

In adults as well as children, mood may have an impact on the way in which a person processes information and comes to a decision. Both the child and the family may be depressed, making it hard for them to accept and agree upon a decision. A consultation focusing on ethics may be helpful in order to consider underlying values and conflicts. However, when depression and other emotional disorders that may influence the child have been ruled out, adults should be more inclined to accept the child’s wishes.[22]

When a child does not protest, this does not necessarily mean that he or she agrees. Personality and upbringing influence how a child accepts a situation.[23] The child may be used to complying with adults or too afraid to argue. When a child refuses a treatment, restraints are sometimes used. This compromises the dignity and liberty of the child and should be used only to prevent self-injury or the injury of another person.[24]

One way of differentiating types of participation in decision-making has been described.[25] This consists of five levels originally developed by Hermerén.[26]

“ 1. A (where A is a member of the staff and B is the child) does not listen to B’s opinions, wishes, and valuations.

2. A listens but refuses to discuss the opinions with B; no consultation, no two-way communication exists.

3. A communicates with B but does not care about B´s answer; B’s opinions, wishes and valuations do not influence A’s actions.

4. A cares about what B says but acts only partly in accordance with B’s opinions, wishes and valuations.

5: A acts in accordance with B’s opinions, wishes and valuations (p 456)[26]:”

Competence

In the literature concerning children’s participation in decision-making, the concept of competence is frequently mentioned. The child must be competent in order to be able to participate in decision-making. If an adult is regarded as being incompetent, this has to be proved, whereas children are presumed to be incompetent.[16] “A child’s competence is a function of age, cognitive abilities and personal experiences" (p 300).[21] When there are doubts about the child's capacity, an assessment is required.[24] However, it is difficult to establish whether or not a child is competent to make a certain decision, perhaps more difficult than in adults. A child can have a general competence, which can be established by a test, and still be incompetent to make a decision regarding health care issues.

At age 18 years, a person in Sweden is permitted by law to make decisions about his or her health, but many children are competent to make decisions when they are younger than that. In some circumstances adolescents under the age of 18 may make decisions without their parents' agreement, especially if they live on their own. For instance, girls under the age of 18 can be given birth-control devices or abortions without the consent or knowledge of their parents.[27] They may also decide about treatments for sexually transmitted diseases, pregnancy, alcohol and drug abuse, and psychiatric problems.[28] Teenage parents are allowed to give consent for their children concerning matters about which they would not be allowed to give consent for themselves.[29]

Tests to determine the competence of a child are developed for "normal children" without taking into consideration the particular situation. The individual child is compared with expectations for "normal behaviour" and the child's cultural background is not taken into consideration.[30] The tests are also performed under ideal conditions rather that during more realistic situations, and do not take into account the child's expectations, personal goals, beliefs and prior experience.[31] For instance, children who have experienced prior hospitalisations are usually more competent to decide about issues that are new to less experienced children, even if the children are of the same age and maturity. Verbally competent children who are able to argue and discuss issues with staff members may reach a compromise that is difficult for less verbal children. A child who has been used to participating in discussions at home, and whose views have been appreciated, is probably better equipped to engage in more serious discussions that may take place when the child is hospitalized.

The competence of the parents is influenced by the situation and their own security. A sense of security when one’s child is hospitalised may be attained in different ways, e.g. security derived from trusting that the professionals know how to take care of the child, security from having control over what is happening to the child, security derived from being the one who knows the child best.[32,33] All mothers have similar concerns for their child,[12] but social circumstances may determine their success in acting as the child’s voice. Being at the same social level and understanding the language of the medical staff, makes it easier for parents to safeguard their child’s interests.

On comparing parents who gave consent for their children to participate in clinical research with parents who did not, it was found that parents who gave consent “exhibited less uncertainty in their decision making, were more trusting of the medical system, had greater understanding of the research, and believed that the environment in which consent was sought was less pressured than nonconsenters” (p 819).[34]

The child’s best interests

Everyone involved in decisions concerning a hospitalised child would agree that the decision should be made based on the child’s best interests. However, opinions could differ about what that means. Perhaps, what is said to be in the child’s best interests is in reality in the best interests of the family.[35]

In a study on life-saving decisions, it was found that the family’s wishes were more important to nursing staff than to medical staff, who considered prognosis to be of greater importance.[36] Parents are usually most suited to judge what is in the best interests of the child. However, the parents’ own distress regarding the child’s condition may prevent them from giving proper attention to the child’s needs and wishes.[24] Their own anxiety and lack of knowledge may influence their arguments. The parents’ particular values and beliefs may not always be in the child’s best interests and may even limit the child’s possibilities. Competing interests of other family members must also be taken into consideration.[37]

When comparing how parents and healthcare providers make decisions, it was found that parents were influenced by the information they had been given by professionals. The healthcare providers were influenced more by the outcome for the child and discussion with family members.[38]

Knowledge

The most common reason for parents to seek care for their child is that they have realized that something is wrong with the child. It may be a visible problem or noticeable behaviour changes. Sometimes, however, parents do not notice anything and illness might be determined by tests or examinations. In such cases it might be more difficult for parents to accept the child's illness and need for treatment.[30]

The concept of information and its value is commonly used in situations where decisions about the child's care have to be made. However, information is usually one sided, the professionals inform the parents and the child about important matters concerning the hospital admission and the parents inform them of the child's illness. There must be communication in order to emphasize the importance of the participation of everybody involved in the necessary decisions. The parents and the child have to inform staff members about the child's condition and, when staff members explain about procedures, they have to confirm that the family members have understood. It should be emphasized that children and adults vary in their need for information,[29] and that this should not be forced upon patients or their relatives.

Receiving understandable information is crucial for making decisions. ”The information they are given from healthcare professionals figures most frequently and most importantly in their decision making”(p 1523). [38] Consequently, the communication that takes place when an important decision has to be made must not be hurried. The more important the decision, the more time it should be allowed to take. If parents do not receive sufficient information from staff members, or if they do not comprehend what has been said to them, they may turn to other parents who have had similar experiences. This communication process will be especially important if they have not received sufficient support and advice from healthcare providers,[39] possibly because they are in the same situation and at the same level regarding knowledge and understanding. However, information from other parents may give rise to a misunderstanding and result in wrong decisions.

Parents often claim that they have not received enough information[40] or optimal information, or that they have not understood the information they have been given. They are usually encouraged to ask questions, but to do that they have to know which questions to ask. As one mother said, “They keep asking me if I have questions, but I don´t even know what to ask” (p 14).[41] When people do not know what they are missing, they cannot ask for it.

Reasons vary as to why parents make one choice and not another. These can include “not having a real choice, considering likely adverse effects of treatment, maintaining my child’s dignity or knowing my child’s preference”(p 1236).[42] When asked, parents may not wish to make a final decision but instead want to participate in the decision process.[13]

Values and attitudes

The values of an individual often determine how that individual acts in different situations and towards other persons. They also influence a person’s decisions, and it is important to consider values when different treatments are discussed because conflicts may otherwise arise.

Sometimes the medical facts and individual values differ in terms of importance, which influences how discussions are conducted. Professionals may believe that family members have the same values as they themselves have because they all belong to a supposedly similar culture. In dealing with families from obviously different cultural backgrounds, staff members tend to be more sensitive about possible differences in values. These are easier to accept when staff members know that the family originates from another country or has a different religion.[43] The more similar the families are to oneself, the stronger is the assumption that values are shared.

The attitudes of staff members are of utmost importance regarding children's participation in decision-making. If a staff member values a child as a person with the right to an opinion, he or she listens to the child and tries to satisfy the child's wishes as far as possible. In a study using a scale to investigate children's participation in decision-making, it was found that children who wanted to take part were given information until they understood and were satisfied. In other cases, the children's wishes were ignored or sometimes not even sought.[14] How staff members behave, both verbally and physically, also affects parents with respect to how much they dare to assert their opinions and support the child's wishes.

Roles and partnership

In recent decades parents have became increasingly involved in the care of their hospitalized child. Consequently, they participate more in decisions regarding the child. If a child refuses a treatment, the parents can either support the child or take the staff member's side. The role of staff members in acting in the child's best interest is similar to that of the parents, but opinions of professionals have greater weight. An action rarely takes place if not supported by the responsible nurse.[23] It is important that parents and nurses discuss the role that parents are supposed to have.

Parents have different expectations; some want to participate in care actions that are impossible for other parents to deal with.[32] Nurses and parents also have different perceptions of their individual roles.[44] Parents want to participate according to their own choosing,[45,46] and some want a collaborative role instead of being active in decision-making.[47] Through guidance, support and negotiations between parents and nurses it should be possible for parents to participate according to their own wishes.[48,49, 50] The participant's role in decision-making varies with the context of the person and the situation. The patient's role expectations, attitudes and knowledge regarding the facts involved in the decision that has to be made should determine the patient's role.[51]

There is supposed to be a difference between just participating in the child's care and being part of a partnership. Sometimes participating in a partnership means that everyone is participating on equal terms, whereas in other cases this could involve just doing what others tell one to do. Working as partners is viewed as an ideal situation when children are hospitalised. However, parents need to have a say about whether they want to be part of a partnership or if they want to leave all decisions to professionals, or something in between. The responsibility of each member of the partnership must be established. Who should decide about the responsibility of each member? The professionals are in charge of deciding about partnership and nurses may feel that, since the parents are seeking help for their child, they are less able to participate in the child's care.[52] Families who are frequently in hospitals are more accustomed to negotiating, and they subsequently have an easier time achieving the role they want. More experienced nurses who feel secure in their profession are more able and willing to negotiate than less experienced nurses.[53]

During a medical examination, the physician and the parents usually take the initiative in terms of conversation, but rarely the child. The physician directs most of his or her comments to the parents, while the child is addressed mainly during the physical examination. Most comments by the parent and the child are directed to the physician, and rarely to one another. The older the child the greater the number of comments addressed by the physician to the child.[54] Parents are expected to participate in their child's care. Sometimes they may not be asked to do so, but their roles are implicit in their being there. When the child is discharged from hospital, the parents are expected to take responsibility for ongoing care at home. If they do not agree to do that, the child may have to stay in hospital. Thus, since alternatives are lacking, there may be no real possibility for the parents to refuse to take on this responsibility or to negotiate in terms of roles.[55]

Power

All patients are dependent on those in charge of their health care. Some individuals are able to handle the situation better than others, depending on their strength, verbal capacity, social circumstances and network. Parents of a sick child are in the same dependent situation they would be in if they were patients themselves. Power in healthcare is exercised in various ways. Those in charge of health care resources and facilities have the power to decide which care to give to a certain patient. This power is expressed in the concept "owning the patient"(p 213), [56] and it has been suggested that "the doctor owns each patient who is admitted under their responsibility, and it may be equally true that nurses in charge of the co-ordination of the care feel the same way". If a staff member has the feeling that he or she owns the child, a conflict might arise regarding the child's best interests.

Another important part of power is knowledge. A patient can easily be encouraged to accept a decision by the use of knowledge that the patient does not have. When parents are reacting emotionally, the way a choice is presented to them may have an influence on their decision.[57] Being very positive about one treatment and emphasizing its advantages may induce the person to choose that treatment. In building a relationship with the parents, the parents are made to want to do the right thing, which may be a kind of masked power relation that minimizes the potential for resistance.[58]

Economy

Research and development in health care have made many new treatments possible. People in general are aware of this and may demand such treatments, which may prolong the hospital stay and increase costs. Resources do play a role when decisions in healthcare are made, although this should not be the case. When deciding about spending a large amount of money on one patient, there is naturally a conflict between the benefit to the population and the needs of an individual. The costs may have to be related to the outcome of a treatment.[59]

Parents’ participation in the child’s care is not always simply for the benefit of the child; the aim may also be to lower costs.[52] By being with the child, parents learn about the child’s illness and its treatment, which means that the child can be discharged earlier. Staff members can be reassigned to other patients and productivity may be increased. Although more time has to be spent on instructing parents when they, instead of hospital staff, care for a child, the hospital costs are decreased.[60]

DISCUSSION

In this article we have analysed and identified from the literature published in the period 1994-2004 important factors that influence decision making in paediatric care. However, in spite of painstaking data searches, we may have missed some articles and the topic may have been discussed in articles without it being obvious from the key words or the abstracts. The articles cited often report results from small research populations, thus not allowing definite conclusions, but they have nevertheless been referred to in the text. The review was not conducted as a systematic survey because the aim was not to determine an answer to a specific research question but to explore the field. However, the literature review was carried out in a systematic manner.

The articles identified were almost exclusively from Scandinavia, the USA and northern Europe. Only two English language articles were found from Asia and Africa but there may be more research on the topic written in native languages. The uneven global distribution of publications in this area may reflect the views and interests of various parts of the world concerning issues of healthcare. In countries with limited resources it may be more important to satisfy basic needs such as for food and shelter than to spend time pondering who should make decisions about health care. Decision-making in healthcare might be a problem of more affluent lifestyles.

Working with the whole family poses a challenge for professionals when they have to determine the roles of parents and the children in making decisions. Paediatric nurses play a key role in promoting the right of children to participate in decisions about their health and incorporating this into the ward philosophy and values. We work closely with children and their families and have important roles as advocates, informants, and communicators. The advocacy role involves protecting children's right to self-determination, enabling them to participate in decisions and have their wishes, goals and views considered in relation to individual children and for sick children as a group. However, ethical principles that provide guidance in the care of adults are not sufficient when caring for children. Models developed for adults presume the patient to be autonomous, with a stable sense of self, mature cognitive skills and established values, which are characteristics that are undeveloped or underdeveloped in children.[3]

The importance of making a decision depends on the seriousness of that decision and its consequences. A decision can be difficult to make if there are several equally good alternatives, if it is hard to make a choice, or if the decision will have drastic consequences, such as when it involves refraining from life-saving treatments. A decision can be made easily for other reasons such as if there is only one acceptable alternative or the consequences of the decision are unimportant (e.g. a medication in either tablet or liquid form). Such considerations probably take place, implicitly if not explicitly, before a decision is made. It is the difficult decisions that give rise to conflicts. The first question to be raised is what constitutes a correct decision. Is it supposed to be correct regarding short-term or long-term consequences, or the consequences for the child and/or the family? Are economic aspects involved? Such questions have to be discussed in order to avoid conflicts.

The concepts of consent and assent are used to adapt the children's' different ages and levels of maturity to the actual decision. The question is how helpful these different concepts are to caregivers? "Calling the child's agreement consent or assent and the parents' proxy consent or parental permission does not tell the practitioner how to respond to them or how they differ"(p 492). [61] Independent of the name of the concept, it is important that children do not take too much responsibility for decisions, which could deny them the protection they need and make them vulnerable.[37] Walker & Doyon[16] contend that the "best interest standard" is paternalistic in nature and emphasizes the importance of adult decisions made on behalf of children, rather than children's active participation in the decision-making process.

Power should not be an issue of importance in health care, but it is, and it is often expressed by competence and knowledge. A person with general competence behaves in a particular way and is not greatly influenced by authorities, which may be reflected in the way that professionals treat a person. The same is true with knowledge. Even if an individual has little knowledge about health care, that person's general knowledge becomes obvious by his or her way of talking and gives him or her a kind of security. Having competence and knowledge makes it easier to clarify what one does not understand and to ask professionals to use understandable language. In addition, such qualities are often associated with financial resources and may be reflected in clothing and toys. A person with obvious competence and knowledge is probably capable of negotiating when decisions have to be made. Competence is always considered with respect to a specific situation, and its development could be described as a continuum from full competence regarding a certain issue on a special occasion to total inability on another occasion.[3]

For professionals, it is easy to use competence and knowledge in order to make patients choose certain alternatives. Today, staff members are encouraged to use language that lay people understand, but the fact that they have knowledge about medical and nursing care makes them seem to be superior when it comes to making decisions. The attitude of professionals determines the extent to which a patient or a parent participates in decision-making. The child and family may be treated as team members and their contribution valued as necessary and important. During communication between staff and the child and family, the family may have the feeling that professionals know best and that they have to accept hospital rules and routines. The preliminaries carried out on hospital admission is usually dependent on the values of staff members and determine the roles that the child and family are supposed to play during hospitalization.

How important is it for children to participate in decision-making? It is probably that children are like adults, so some want to be involved whereas others do not.[62] In a compilation of 59 separate reports from voluntary bodies and statutory organisations published by the Commission for Health Improvement,[63] children and teenagers said that they feel that they have the right to participate in decisions about their treatment rather than being passive recipients of care. However, they also said that they are unhappy with the lack of communication and that they do not think they were sufficiently involved in the decision-making process. A prerequisite to be able to participate is to be allowed to do so and to receive information that is adapted to the child’s needs and wishes, and is about the alternatives ant the opportunity to reflect, to ask questions, and also to refuse to participate. Professionals should not take it for granted that all children want to participate in decisions but should try to find out if they want to participate and if so to what extent.

Conclusion

The clinical application of previous publications on this topic would be to find out to what extent children and parents want to participate in decision making. As has been shown, it is important to keep in mind that decision making is a process in which families want to take part. However, usually they do not want to make the decision. Going through this process can be time consuming, but it probably saves overall.

For further research we suggest empirical studies on the topics falling under the subheadings in this article: How should a child's competence to make a specific decision be determined? What knowledge should parents have to enable them to make a decision? How much have they understood of the information they have been given? What are the values of the persons involved in a decision? How do values influence that decision? What roles do parents want to have? What roles are they given, and why and by whom?

Table 1 PubMed search

	MeSH terms	No. articles found
#1	decision making	66 697
#2	#1 and health care	22 696
#3	#2 and nursing care	3 407
#4	#3 not psychiatry care	3 355
#5	#4 child*	164
#6	#5 not child birth	149
#7	#6 and parents	57

Table 2 CINHAL search

	Thesaurus	No. articles found
#1	decision-making clinical	768
#2	#1 and child*	156
#3	#2 and parents	18

* and all endings

Table 3. Overview of the identified articles

Article type	North America	Europé	Asia	Australia	Total
Original	10	17	1	1	29
Overview	4	3			7
Theoretical	4	1			5
Discussion	5	3			8

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